

Planning for the Care You Need at Home



AGING (i)fe CARE™
A S S O C I A T I O N

The experts in aging well.

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Once children are grown, they commonly move away from home. Some families stay close together, while others live relatively separate lives for many years, seeing each other during sporadic vacation times and special occasions. But generally, parents and adult children live their lives quite independent of one other. Eventually, however, an event occurs, or a change happens, that stops the family in its tracks and demands a new approach to how they communicate and interact. This can be a serious accident, an unexpected illness, a death, or the realization that slowly, over the course of many months or even years, a family member is losing, or has lost, the ability to competently manage their own life.

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For families near or far, this is a very challenging time. During a crisis, a family can flounder, separate, and fail to cope. Sometimes stopgap, crisis-response measures are used to handle the particular event, without addressing the possible changes needed in roles and responsibilities, or in how decisions are going to be made.

On the positive side, families can grow together, cooperatively and with care. It is an opportunity to address old wounds, hurts, or misunderstandings, resolve stress, or seek forgiveness, thus allowing the family to reorganize itself to help a family member in need. As each member demonstrates talents or expertise, others have a fresh opportunity to appreciate each other's contributions and see one another in different ways. This is the challenge – to have a new conversation on some rather difficult subjects when family members are injured, ill or clearly growing old and frail.

This e-book covers some of the aspects of getting care when the time comes, how to get that help, and how your family can arrange for help when you might not be able to make some decisions for yourself. It will share some stories to demonstrate and bring these issues to life.



Making Decisions Can Be Challenging

Most of us want to maintain the freedom to make decisions for ourselves. So when circumstances require new and possibly unwanted changes in our lives, we can feel unsure or unprepared on how to respond. You might resist suggestions on how to handle these changes, which might include health challenges, your daily routine, or activities that you consider part of your normal day, such as driving your car.

You may find it helpful when family members help you research issues, find resources, and support your decision-making. However, as issues become more and more complex, they can be overwhelming or beyond the expertise of friends and family.

When you are facing complex problems related to aging and health issues and need multiple services at home or referrals, professional assistance can be a lifesaver.

This e-book is designed to help support you in making the decisions that are right for you.

Many Older Adults Live at Home

Contrary to what many believe, most people live and die in their own home. Here are some interesting statistics:

The percent of older people 85+ years living in nursing homes has actually decreased by half from 1998 (19.8 percent) to 2013 (10 percent).

Overall, the percent of all individuals 65+ living in nursing homes has decreased from 4.2 percent in 1998 to 3.5 percent in 2013. This is due to the increase in alternative forms of housing that provide some supportive services, but not the entire range of services provided in nursing homes.

The majority of men (71 percent) over 65 live with a spouse, while only 45 percent of women over 65 live with a spouse. These figures have not changed dramatically since 1998, when 73 percent of men lived with a spouse and only 41 percent of women did.

Aging Life Care™ Managers Can Help

You don't have to go it alone. Aging Life Care Managers are generally professional social workers, nurses, or other health care professionals who have special expertise in working with older or disabled adults and their families. They can ease the burden of dealing with very taxing situations.

Who they help | An Aging Life Care Manager provides invaluable assistance to individuals and families who need help at very challenges times. They can help you transform an overwhelming experience into one that rallies resources and helps you feel that your needs and preferences are being dealt with in the best way possible.

A Care Manager can prove particularly useful for people who have no families, whose family members live far away, or who have changing circumstances or complex problems that have already proven to be difficult for the family to manage without professional advice.

Their role | Your Aging Life Care Manager determines how to help you and your family by:

- Exploring the physical, emotional, financial, and social problems you are experiencing.

- Doing an assessment of how you are functioning at home, and the help you have available to you from family, friends, and neighbors.
- Assessing any medical conditions you are being treated for and what your treatment consists of.
- Evaluating your financial resources.
- Recommending ways to improve your daily functioning.
- Providing you with information on the resources and service options available to you and the costs of these options.

After the assessment | After everyone agrees on a plan, your Care Manager can arrange for the services you need. They will continue to provide ongoing monitoring and reassessment as your condition changes over time.

Fees | An Aging Life Care Manager generally charges an hourly fee for their expert advice, although some charge a flat fee based on the type of services they provide. These fees are not covered by health insurance policies, unless you have long-term care insurance, which may cover the cost of the Aging Life Care Manager's time.



Patrick and Mary's Story

Patrick and Mary have lived in the same home for 55 years, moving in just after they got married. They raised their children here and are now enjoying the house and yard during their retirement years. During the past six months it has become clear to Mary that Patrick's memory has become seriously impaired and his behavior a little troubling. He constantly gets up at night, sometimes to go to the toilet and sometimes to just wander all over the house, getting a snack, turning on all the lights, and making it impossible for Mary to sleep. Sometimes Patrick is confused; and once he accused Mary of being a stranger.

Mary took Patrick to their family doctor who recommended that a specialist examine Patrick. The specialist, a geriatric psychiatrist, diagnosed an Alzheimer's-type dementia. He prescribed several medications that seemed to help Patrick remain calm, but Mary was afraid to leave him in the house alone. Their adult children are very attentive and caring, but they have families and jobs that keep them very busy.

Mary had to do something. So she hired a woman who had taken care of a friend to stay with Patrick when she went out. Mary liked this woman, who was very nice, but she was not reliable, canceling at the last minute three days in a row. Mary's daughter, Sarah, suggested they meet with an Aging Life Care Manager who proved to be very helpful. She supported Mary's need to have a safe place for Patrick while she shopped, spent time with friends, or just had time to be home and take a nap without worrying about her husband. She recommended that Patrick go to the Special Care Adult Day Center in a church about four miles from their home three days a week. Mary was afraid that Patrick wouldn't want to go, since he was not an "arts and crafts" type of man, but the day center staff assured her that they had many different types of activities, and they would help Patrick find something he enjoyed doing. To Mary's surprise, Patrick loved going to his "club," as he called it. Since they had long-term care insurance, the Aging Life Care Manager helped Mary apply for the appropriate benefits and the insurance covered the cost of the day program. The Care Manager meets with Patrick and Mary about once a month, and is available whenever a crisis occurs or Mary has concerns and questions.

What if You Become Homebound?

If you are recovering from an acute illness, you may be eligible for home health services that are paid for by the Medicare program. An Aging Life Care Manager can help you access licensed home health services by facilitating a conversation with your physician about your need for skilled nursing services, physical therapy, occupational therapy, and/or speech therapy in your home. This is an important conversation to have with your doctor and discharge planner if you are in the hospital or a nursing facility and need to decide on and plan for services in your home once you are discharged (and discharge planner if you are in the hospital or a nursing facility).

However, Medicare will only pay for these services if you are “homebound.” Homebound is defined as only leaving your home for “medical treatment or short, infrequent absences for non-medical reasons, like attending religious services.”

You may also receive help from a home health aide under the supervision of a professional nurse or therapist. A physical or occupational therapist can evaluate your home and recommend equipment (such as guard bars in the bathroom) that will improve your safety.

Accessing services | These services must be obtained from a state licensed home health agency certified to provide Medicare-reimbursed services. They may be freestanding agencies, or they may be part of a large, hospital-based organization. Licensed home health services are usually time-limited, ending when you have met the goals of treatment and the need for the skilled care has ended.

If you have enrolled in a Medicare Advantage program, you may also have access to additional services such as home visits after a hospitalization.

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Other Home Care Services

Many other care services are provided in the home but are not licensed or paid for by Medicare. An Aging Life Care Manager can help you understand what they can offer, access reputable services, and monitor them on an on-going basis.

Non-Medical Aides, Companions, and Homemakers

There are many types of paid care giving services available—often called non-medical aides, companions, and homemakers—who many people hire privately. If you do, you or your family should check at least two work-related references, develop a specific set of tasks and expectations for the caregiver, arrange to pay all appropriate taxes, and have the required insurance coverage. Your accountant can give you information about taxes and insurance, or you can use an online payroll service. As long as you document that you have paid the Social Security and other taxes, your expenses to hire your own caregiver may be tax deductible as a medical expense (discuss with your accountant or an IRS representative).

Caregiver services can also be arranged through an agency. While this may cost more per hour than hiring an aide yourself, hiring an agency assures you of coverage when the aide is sick, on vacation, or quits. The agency also carries liability insurance and is responsible for all employment taxes and employee bonding. An Aging Life Care Manager can help you find a reputable agency and get important questions answered, such as do they check police and driver license records; do they provide supervision; how do they handle cancellations; and how long have they been in business? The agency should have

a brochure and fee schedule that explains how they provide services and what the fees are, including how they handle overtime and holidays.

Home Delivered Meals

Commonly called “Meals on Wheels” or “Mobile Meals,” these programs provide one or two nutritional meals delivered daily to your home, often by volunteers to keep the cost modest. These meals can be a temporary means of providing you with the nutrition you need when you are unable to shop and prepare food, or it can be a long-term solution to this problem. Home delivered meals usually arrive between 10:30 a.m. and 2 p.m., with a hot lunch for the midday meal and a sandwich, fruit, dessert, and milk or juice to be refrigerated for the evening meal.

In many cities there are companies that deliver food and household supplies directly to your home, which you can order online or by telephone. Meals can be customized to fit dietary needs and tastes.

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Technology Helps You Stay Safe at Home

There are numerous technological solutions available for use in your home.

1. **PERS, Personal Emergency Response System.**

This is an electronic alert system that uses your home telephone or a GPS system, or a combination of both, to send a distress call to a central call service. A “help” button, usually worn around the person’s neck or wrist, activates the call.

These systems may include an alert that is triggered by a fall.

- Some systems have two-way voice communication so the call center can speak to you to determine if the alert is a false alarm or you need immediate assistance.
- Usually these systems require several designated responders – individuals who live close by and have a key to your home.
- When the responder gets to your home after the alert has been activated, they communicate with the call center to send an ambulance if needed.
- These medical alert systems usually charge a one-time set up fee and then a monthly subscription fee for being connected to the call center.

2. **Home monitoring through electronic sensors.**

These include wireless motion detectors, video cameras, and even temperature sensors that send information to a remote computer that can be monitored by family members or by a health care provider. The sensors are programed to identify situations that are out of the ordinary. For example, if a motion detector is set up to monitor medication, it can send a message to the designated contact if there is no motion during a time period when someone is expected to take

medication. Or the motion detector can alert someone if a door is opened. There are many different electronic sensors that are directly related to monitor specific health conditions, including blood pressure, oxygen levels, weight, or body temperature. Usually these are monitored by a licensed home health agency or a medical office, allowing for remote monitoring of chronic care conditions, which can help avoid emergency medical problems. Pressure sensors (usually a mat with an alarm) can be placed in a chair, bed, or on the floor to alert a caregiver of movement or activity. Or if wandering is a concern, door and window sensors can be added. The cost of these electronic home monitoring systems vary; but generally there is a cost to purchase or rent a system plus a monthly monitoring fee.

3. **Interactive wireless communication systems.**

Home communication systems structured for family communication use the internet and a computer monitor or tablet (often with touch screen capability) to have conversations and share calendars, pictures, videos, or text messages. Medically oriented wireless communication systems send data to a central medical office for monitoring a patient’s health in real time. If a system is put into the home by a medical provider, it may be paid for by health insurance. This type of medical communication system is often leased, not purchased, and the monthly fee depends on the level of service. The home communication systems for families usually require purchasing a special television, monitor, or tablet and downloading software. Generally, there is a monthly fee for using the software.

Less high-tech devices, such as room monitors, provide an inexpensive way to communicate throughout your home. New electronic systems are being developed every day and an Aging Life Care Manager can help you find the technology that is right for you.

A Story About John

John, who lives alone, fell in the shower and hit his head, but he managed to crawl to the telephone to call his only daughter, Jamie, who lived about two hours away by car. Jamie called 911, and then rushed to meet them at the hospital. After a hospital stay of six days, during which John was treated for a mild heart attack, concussion, and sprained hand, his doctor arranged for John to meet with the hospital discharge planner. When the discharge planner heard that Jamie didn't live in the same town as her dad, and also had a full time job and three teenage children, she realized that John needed some help. She referred them to an Aging Life Care Manager, who arranged for John to return home and receive follow-up care through a licensed home health agency. The Aging Life Care Manager also arranged for a physical therapist to visit John three times a week for strengthening exercises, a nurse to monitor his medications, and a home health aide to come three times a week to help him take a bath. She ordered home delivered meals so that John did not have to prepare his own food. Jamie and the Care Manager recruited two neighbors who agreed to be responders and accepted keys to John's home. With those individuals in place, they installed an emergency alert system. The Aging Life Care Manager made bi-weekly monitoring visits to John's home to make sure that as John recovered, his mix of services was adjusted so that he did not experience a new crisis.





Time Out for You

Being home day after day can become isolating and get very boring. If you have a primary caregiver, they will need some time off to work, shop, or simply have time away from care giving duties. Adult day services provide a safe place for you to go during the day to give your primary caretaker a break. This also gives you fresh faces and new people to talk with. These services are often located in churches, retirement communities, or freestanding centers. Generally open for 8 – 12 hours a day, they often cost less than hiring a paid caregiver in your home. They provide meals, social interaction, and in some centers, bathing, therapy, and even occasional weekend overnight care (often called respite care) so that your primary caregiver can have some extended time off. Many of these centers also provide transportation. Adult day services may be covered by long-term care insurance policies.

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A Story About Joan

Joan is an 83-year-old widow who has some short-term memory loss, although her long-term memory is relatively good. Her only son, Roger, lives 1,000 miles away. Joan's physician questions whether she can continue to drive and is concerned about her memory. Joan has been coming to his office, and calling numerous times, trying to understand an invoice she received in the mail, and asking about a new medication he had prescribed. He contacts and asks an Aging Life Care Manager to meet with Joan. When the Care Manager met with Joan in her home, Joan could not find Roger's phone number, and the doctor did not have it in his files. The Care Manager looked up his name and address on the Internet and sent him a short note explaining the circumstances through which she had met his mother, the services she offered, and the fees she charged.

Roger engaged the Care Manager to develop a plan for assisting his mother so she could remain at home, which he knew was her desire. The initial plan called for the Care Manager to visit Joan every two to three weeks, and to arrange for an aide to take her shopping and assist with housework three times a week. This understanding, respectful support helped Joan agree to voluntarily sell her car. The Care Manager also purchased a medication cassette for Joan, which she filled during each visit. The Care Manager kept Roger informed regularly about Joan's health status and social situation. It provided him with peace of mind, knowing that if a crisis should occur, there was an experienced professional on whom he could rely until he could come be with his mother.



Care at Home at the End of Life

Hospice care | This is a special service that uses an interdisciplinary team to provide care and comfort to individuals at the end of life, and to their families. Medicare pays for hospice services if your physician believes you have a life expectancy of six months or less. Although this service is most often used by people with a diagnosis of cancer, it is available for any diagnosis as long as you agree that you want palliative (comfort) measures, rather than medical treatment that you expect to cure your illness.

It is the philosophy of hospice that the dying person should be pain free, in comfortable surroundings, cared for with dignity, and not alone. Many people speak generally about not wanting to be “kept alive by machines,” but do not realize that even having an antibiotic to treat an infection is a form of treatment, since antibiotics are so commonplace.

Making the decision to engage Hospice | While refusing treatment allows for the natural progression from life to death, this is not a decision that you can make easily or quickly. Some people, even when their physician has made it very clear they are dying, continue to desire that all efforts be made to prolong their life. You may wish to think about the philosophy of hospice services well before you need them, and discuss your thoughts and feelings with your family – a conversation that Aging Life Care Managers are adept at facilitating.

Realizing that one’s life may be ending soon can be very difficult to accept. And talking about the feelings that come with such a stark reality can be hard as well. It might feel impossible for you to openly discuss your eventual death with your family. An Aging Life Care Manager can help you sort through your feelings and have an important conversation with your family that explores how hospice services can assist you in having “a good death.”

Hospice providers | A specially trained team of physicians, nurse’s aides, spiritual counselors, social workers, and volunteers provide hospice care. It includes the on-call availability of professional staff to respond to any changes in your condition 24/7. Hospice services include any medical equipment needed, such as a hospital bed and any medication to manage pain. Since the hospice team’s purpose is to assist the family throughout the dying process, it continues with bereavement counseling.

Location | While most hospice care is provided to people in their own homes, hospice services may also be provided in a nursing home, special hospice facility, or special care unit in a hospital. These special inpatient hospice units usually have no visiting hour restrictions, so families are free to come whenever they are able, and stay as long as they wish. Some hospice facilities even have kitchenettes for families to use and recliners for family members to sleep in if they do not want to leave when their loved one is having a rough time or death seems imminent.

You may wish to think about the philosophy of hospice services well before you need them, and discuss your thoughts and feelings with your family – a conversation that Aging Life Care Managers are adept at facilitating.

Change, Loss, Grief, and Life Review

"Growing old is not for sissies!" is a common, and true, expression. As you age, you are forced to confront a series of losses: minor losses – hair, waistline, energy – and major losses, including the people you love and rely on. The sadness and grief you might feel is natural, and it is not easy to "get over it," as one might want or others expect. For some people, religious beliefs can help to soften the blows a long life has dealt them. Other people review their life story, write a memoir, organize their photos, or clean out their attics, carefully choosing objects important to them to keep for now and eventually give to their family or friends. These kinds of activities can help you come to a sense of fulfillment of a life spent as well as possible.

Difficult feelings | However, some feelings can overwhelm you, such as anger, numbing depression, dread, or anxiety. If you find that you are crying or on the verge of crying, every day, or if you feel constantly

angry and fearful yet unable to name what upsets you, you can seek diagnosis and treatment from a geriatric psychiatrist, a medical specialist who can detect the difference between normal grief and clinical depression.

Medication and therapy | For some people, depression and anxiety can actually be an organic illness that can be treated with mood-stabilizing medications. Many older people grew up with a mindset that you "tough out" your problems. They find it hard to believe that feelings are caused not only by life's circumstances but also by biochemical changes in the brain. A course of anti-depressants or anti-anxiety medication, coupled with individual therapy for those willing to consider it, can significantly improve your outlook and your ability to handle your daily life. There are even programs that involve a physician, a psychiatrist, a case manager, and others who collaborate with you to provide the most productive course of treatment.

The sadness and grief you might feel is natural, and it is not easy to "get over it," as one might want or others expect.



Taking Action and Making Decisions

Accepting assistance from others – including your adult children, other family members, or friends – with grace and appreciation can provide relief and pleasure, particularly when you realize that you need help. An Aging Life Care Manager can help you sort out difficult feelings by hearing your life story and helping you put your current life into perspective. They can help you understand what you need to accomplish to continue managing your life.

An important step is to choose a person to act as your Health Care Power of Attorney. This is often a family member, sometimes not. But it must be someone who you trust very much. You need to discuss with that person what your own preferences are regarding making health care decisions for you if/when you become unable to make your own decisions. Your Aging Life Care Manager can help facilitate this conversation and also help you to write down your desires about such questions as:

- Do I want my life to end pain free?
- Do I want to accept or avoid life-prolonging interventions under various circumstances?
- How /where do I want to be buried or do I want to be cremated?
- What rituals do I prefer for when I die?

Having these discussions before they are needed helps insure that your wishes are followed if you become unable to make your opinions known yourself.

In closing

If you took a poll of older adults and asked each person if they wanted to remain in their own home until the end of their life, most people would say, “of course.” That is a wonderful goal, which often takes a lot of sound planning to be successful. Anything can get in the way – accidents, illness, lack of energy, declining physical abilities – of achieving your desired independence. It is hard to give up even a little autonomy, but asking for assistance can help keep you where you want to be – in your own home. Your family can come together and construct a plan for supporting you in your wishes. If it becomes clear that you all need help in doing that, hiring An Aging Life Care Manager is a wise investment. The Care Manager can facilitate a family understanding of the situation and help everyone recognize what your needs are, help bring on board important services, and provide caring support to you and your family on an ongoing basis.



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